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ABSTRACT

These guidelines were written to help families coordinate the health care that may be needed by a child with spina bifida. The booklet begins with general information about spina bifida. It then discusses the goals of health care, the health care team, the importance of periodic health care, and record keeping procedures. The child's health care needs, development, and educational needs are then examined by age, from birth to age 21. Family support and services are described, including advocacy, human services, schools, family support groups and networks, respite care, transportation, recreation, travel, and siblings. The booklet concludes with a glossary, a list of organizational (primarily in Minnesota) and printed resources for children with spina bifida, and a list of more general resources for children with special health care needs. (JDD)

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Guidelines of Care for Children with Special Health Care Needs

SPINA BIFIDA

EC 301667

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in

Information contained in this booklet is meant to supplement the advice of a physician or other health professional. Ask your physician about your child's specific needs.

Credits

Thank you to the many families, physicians and health professionals who shared their expertise and insight for development of the guidelines. Also, thanks to the members of the Ad Hoc Advisory Task Force for their assistance in planning and developing the guidelines.

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INTRODUCTION

These guidelines are written for families and health professionals. They can also be used by anyone who cares for a child with spina bifida including teachers, school personnel, friends, and relatives. Readers may find different sections of the booklet useful during the child's development.

The primary purpose of the guidelines is to help families coordinate the health care that may be needed by a child with spina bifida. This information may help families determine which services are needed for the optimal development of their child. To do this, families need to understand the health care system and how to use it effectively.

Health care services are a resource for families. They provide information, care, and treatment for children with special health care needs. Families who are actively involved in coordinating their child's care assure their child better health care. This is because informed, involved families can promote communication with and between health professionals. Informed families also understand how the health care plan meets the needs of their child better than anyone else. These parents know when the plan is not working well for their child. They can identify unmet needs or duplication of services. Parents are encouraged to actively participate with health care providers to assure that the child's needs are met.

The challenge to health professionals is to serve families appropriately and effectively by providing **family-centered care***. This can be accomplished by providing health care within the context of each family's values, ideals, culture, and lifestyle. The family also benefits from **community-based** services, as close to the child's home as possible.

Each child has different needs. These guidelines list the most common health care needs of a child with spina bifida. ***Ask your doctor how your child's health care needs are different from those listed here.***

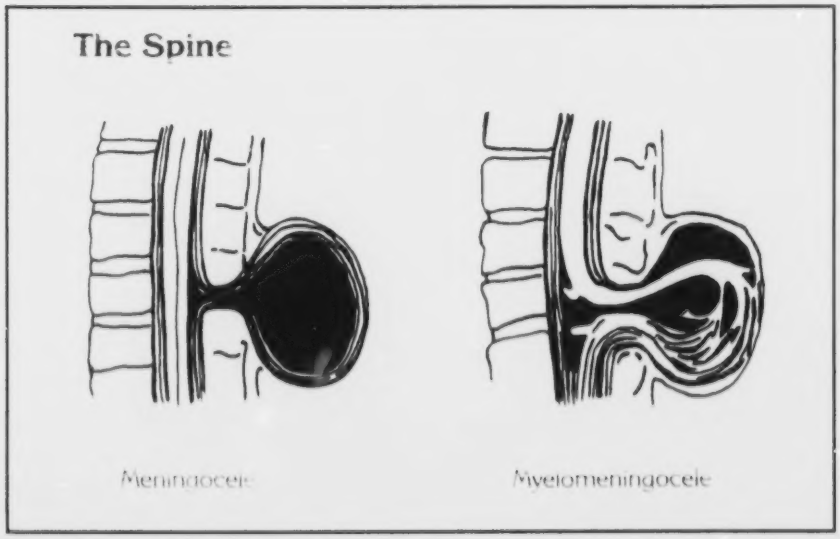
*Words that you see printed in dark type are explained in the Glossary that appears later in this booklet. Turn to the Glossary whenever you are not sure of the meaning of a word in dark type.

GENERAL INFORMATION

What is spina bifida?

Spina bifida is one of a group of defects of the spine, called **myelodysplasia**. There are several types of myelodysplasia. These are the most common types:

Myelomeningocele — The most common defect is myelomeningocele. The spine is open and is abnormally formed. A sac that contains the abnormally formed spinal cord juts out of the back. The sac can be anywhere on the spinal column. The higher on the back the sac is, the more nerves are affected and the more paralysis occurs. Surgery is needed to repair the affected area of the back.



Meningocele — The spine is open with a sac attached. None of the spinal cord is in the sac. Most often, few nerves are affected. Surgery to remove the sac is usually necessary.

Spina bifida occulta — This is when the back of the **vertebra** or spine fail to form, but the membranes, spinal cord, and skin are normal. Sometimes there is a small dimple in the skin where the spine is affected. This condition is very common and requires no treatment.

What causes spina bifida?

Spina bifida is caused by a combination of **genetic** (inherited) and **environmental factors**. Once a mother has had a child with spina bifida, the chances of her having another child with the same condition are 1 in 20. If the mother becomes pregnant again, she may have a blood test (alpha fetoprotein). This test can show if the fetus (unborn child) has a severe case of a similar problem. **Genetic counseling** may be useful to families with a child who has spina bifida.

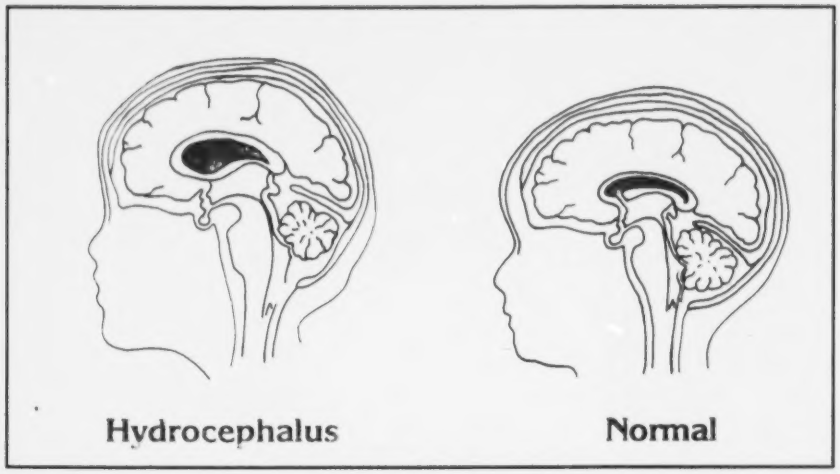
What are the effects of spina bifida?

The effects of spina bifida vary with each child. These are some common health problems:

- Paralysis of the legs
- Lack of reflexes in the legs
- Short legs
- Lack of bladder or bowel control
- Lack of sensation below the area on the back where the sac occurs
- **Hydrocephalus** in some children
- **Club foot** and hip problems in some children

How is my child affected by spina bifida?

The ability of children with spina bifida to move about and control their bladder and bowels varies with the child. The differences depend on the location of the defect in the spinal cord. Surgery is performed to close the defect and prevent serious infection around the brain, but does not change the paralysis. The child's motor skills (movement) may develop slowly. Often the legs of a child with spina bifida do not develop as completely as other children's do.



Many children with spina bifida also have **hydrocephalus**. This is a condition that causes extra fluid inside the brain. It is corrected by placing a shunt (tube) from a space in the brain to the abdomen. The shunt will need to be replaced several times with a longer tube as the child grows. When a child has a shunt, parents should watch for signs of complications. The two most common complications are blockage and infection. The signs and symptoms of blockage include:

- Headache
- Irritability
- Nausea, vomiting, or both
- Changes in behavior
- Changes in alertness
- Bulging fontanelle (soft spot on the head) in infants
- **Seizures**

An infection has the same signs and symptoms and is usually accompanied by fever. If the child has a fever for an unknown reason, the doctor may **culture** the spinal fluid. Sometimes a sample is cultured for 8 to 10 days to find slow-growing bacteria.

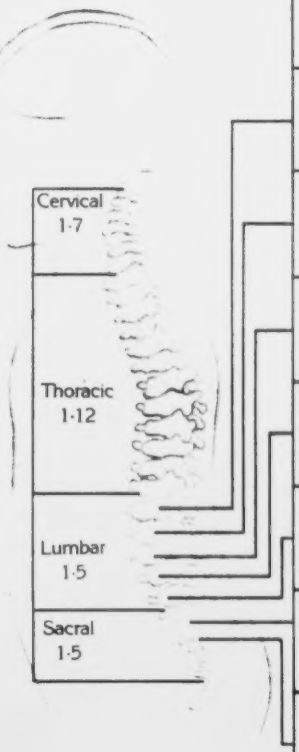
Spina bifida and hydrocephalus can cause mental retardation and **learning disabilities**. However, most children who are treated for these conditions shortly after birth have normal intelligence.

Some other health problems that children might have include overeating and overweight or obesity, short stature, and **seizures.**

Do some people have more severe spina bifida than others?

Yes, some people have more severe spina bifida than others. Some children and teenagers have barely noticeable muscle weakness in their legs. Others may need a wheelchair to get around. The ability of children to take care of themselves varies greatly also. Most children are unable to control their bowels and bladder without medical help. Some need special equipment to feed and dress themselves. Equipment and therapy are available to help the person with spina bifida gain as much independence as possible.

The following chart shows how much leg movement is possible depending on the location of myelomeningocele.



Location of Spina Bifida	The child can
Lumbar 1	lift legs at hips
Lumbar 2	pull legs together (and above)
Lumbar 3	straighten legs at knees (and above)
Lumbar 4	bend legs at knees move feet upward (and above)
Lumbar 5	straighten legs at hips pull legs apart (and above)
Sacral 1	move feet downward (and above)
Sacral 2	move feet and toes (and above)

HEALTH CARE

Many health care providers use the **Family-Centered Health Care Team** approach to treat a child or teenager with spina bifida. Using this approach, health professionals and the family decide together how to make the treatment plan meet the child's unique needs. The family coordinates or arranges the child's health care. This way, the family takes an active role in planning the health care of their child.

Health professionals vary in their knowledge and experience. When choosing a primary doctor or other health professional, ask if he or she has had training or experience with spina bifida. Also find out if he or she is comfortable treating a child with spina bifida. If not, most professionals will offer to refer you to someone with more knowledge and experience in treating the condition.

Other considerations include the provider's communication skills and accessibility to services. Are you comfortable discussing your questions and concerns with the professional? Do they take time to explain treatments, medications, and procedures? Is the office location convenient? Are appointments given on short notice? Your family's choice of health professionals can help your child get quality health care.

Goals of Health Care

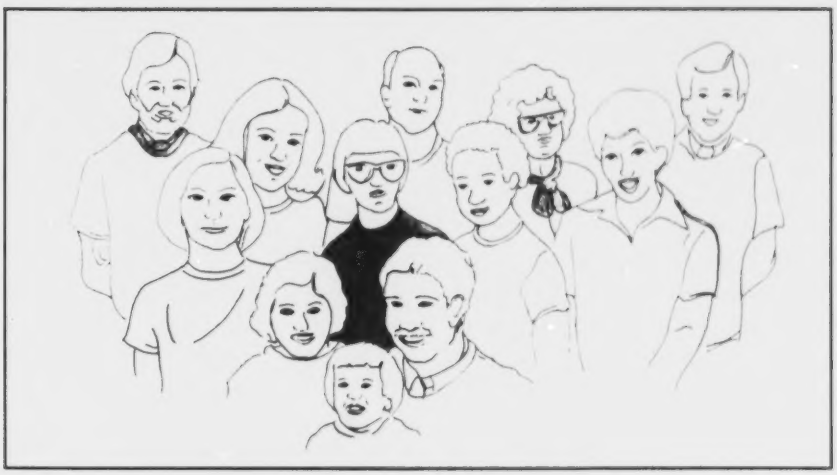
These are the goals of treatment for the child with spina bifida:

- The greatest possible independence and participation in society
- Prevention of secondary problems in physical and mental health
- Knowledge of spina bifida and ability to manage the condition

The family-centered health care team can accomplish these goals by taking the following steps:

- Providing health care team management that fits each family's needs
- Helping the growth and development of the child by providing adequate health care and therapy
- Teaching the child and the family about spina bifida
- Involving the child and the family in making the treatment plan

The Health Care Team



Each child may require a number of services depending on their age and the severity of their condition. The child or teenager with spina bifida may require treatment from many health professionals. The following list describes the type of care that each of these professionals can give your child. Some of the same services may be available from different types of health professionals. When parents coordinate their child's health care, they can make sure services are not duplicated or some needs overlooked.

The Child or Teenager and the Family · The most important members of the team!

- Coordinate the child's health care
- Give personal and family health history
- Communicate with health professionals about changes in the child's condition, treatment plan, and needs

Pediatrician or Family Physician · The primary physician

- Gives well-child examinations
- Prescribes immunizations
- Monitors the child's growth and development
- Monitors child's **nutritional status**
- If the child has a shunt, monitors for signs of blockage and the need to replace the shunt as child grows
- Communicates with parents and other professionals who are involved in the child's care
- Treats illnesses

Neurosurgeon - A physician for brain and nervous system surgery

- Closes the open spine
- Performs surgery to place a **shunt** to drain fluid from the head in a child with **hydrocephalus**

Orthopedist - A physician for repair of bones and joints

- Performs detailed examinations of the bones and joints
- Closes the open spine
- Recommends bracing for the legs when needed
- Manages **scoliosis** or curvature of the spine
- Performs joint and leg and foot surgery when needed

Pediatric Neurologist - A physician for the brain and nervous system of children

- Performs detailed examinations of the nervous system
- Monitors hydrocephalus and shunts
- Manages seizures

Physiatrist - Physician for physical disabilities and **habilitation**

- Evaluates the child's physical function and mobility
- Prescribes braces and adaptive equipment

Urologist - Physician for the urinary tract

- Treats **urinary tract** infections
- Recommends a treatment plan to achieve urine control

Child Psychologist - A mental health professional

- Helps maintain the child's mental well-being
- Performs educational testing
- Recommends appropriate education
- Counsels the child and family on social and emotional issues

Nurse Clinician - A registered nurse with expertise in a specific area of health care

- Provides health education and support services to the family, health professionals, and others involved in the child's care

Public Health Nurse - A registered nurse who specializes in the health of people at home and in the community

- Helps the family coordinate health care
- Gives emotional support to the family
- Teaches the family about procedures and medications
- Provides health services in the child's home
- Makes referrals to community agencies and health professionals

Occupational Therapist - A professional who specializes in improving the use of the hands and arms

- Evaluates and treats the child's muscle tone, fine motor skills, and activities of daily living
- Develops methods for individual independent activities of daily living such as feeding, dressing, and play

Orthotist - Orthotic equipment specialist

- Makes equipment for mobility and independence including braces, splints, and larger adaptive equipment
- Makes adjustments so equipment will fit well

Physical Therapist - A professional who specializes in treatment of large muscles and movement

- Evaluates and treats the child to improve physical function and mobility
- Assists with orthotic and adaptive equipment needs
- Provides parent education for large muscle use in home activities

Registered Dietitian - A professional nutritionist

- Evaluates the quality and adequacy of the child's diet
- Monitors the child's diet and weight to prevent obesity
- Reviews interactions of diet and medications
- Gives preventive and educational counseling
- Develops a nutritional care plan for the child

School Nurse

- Helps the child and family coordinate the child's health care needs in school and school-related activities
- Helps the child and family communicate health information to teachers and other appropriate school personnel
- Helps teachers provide an appropriate learning environment for the child
- Performs special health care procedures and gives medications in school

Social Worker

- Gives counseling and support about balancing family life with managing the care of the child with spina bifida
- Finds community resources such as support groups and financial help

Periodic Health Care

Regular health care visits are important to your child's well being. These visits are necessary to check your child's growth and development as well as his or her spina bifida. The schedule of regular visits will vary depending on your child's age and health. Children are individuals and their needs will vary. ***Ask your doctor if your child's health care needs are different from those listed here.***

- Immunizations
- Regular measurement and graphing of height, weight, and head circumference
- Nutritional evaluation
- General physical examinations by the child's local primary doctor, based on the child's age and health needs
- Examinations by neurologist, neurosurgeon, orthopedist, physiatrist, and urologist, as needed
- Periodic hearing and vision screening
- Discussion of child's development since last visit
- Discussion of symptoms since last visit
- Discussion of medications, treatments, and equipment needs
- Discussion of your questions and concerns

You usually can arrange for many of these services at one visit to a specialty clinic. The frequency of this visit depends on the child's age and needs. In addition to the specialty clinic visit, your child needs to see his or her regular doctor for immunizations, well-child exams, illnesses and other health problems.

These symptoms need medical attention between regular visits:

- Fevers with or without an accompanying illness
- Signs of bladder-infection including: dark, cloudy, smelly, or pink urine or fever
- Changes in the child's behavior
- Any problems with the treatment plan
- Chronic headaches
- Vomiting
- Diarrhea or constipation

These symptoms need *immediate* medical attention:

- Severe headaches with a fever
- Stiff or sore neck with a headache
- Infants with unusual irritability, crying, or unusual postures
- Pressure sores
- Swelling and warmth in the child's legs and feet
- Lethargy (drowsiness or indifference)
- Signs of a blocked shunt: headache, nausea, vomiting, irritability, changes in behavior, changes in alertness, **seizures**

Any time you have a health concern and are unsure if it needs medical attention, check with your doctor, clinic nurse, or an emergency room nurse.

Record Keeping

Record keeping is an important part of coordinating your child's health care. Care can be complex and may require visits to many professionals. Some parents find it helpful to keep their own records. Other parents prefer to rely on their health care provider's records. If you keep your own records, you can use a loose-leaf notebook that can be divided into sections to fit your needs. A calendar can also be used to keep records. Section topics may include the following:

- Names, addresses, and phone numbers of health team members
- Appointment dates
- Surgeries, tests, and other procedures and the date
- Laboratory test results
- Medical equipment - type, date received or adjusted
- Daily care plans - treatments, medications, home activities
- Medication information
- Changes in symptoms and illnesses
- Records of your child's growth and development
- Immunization records

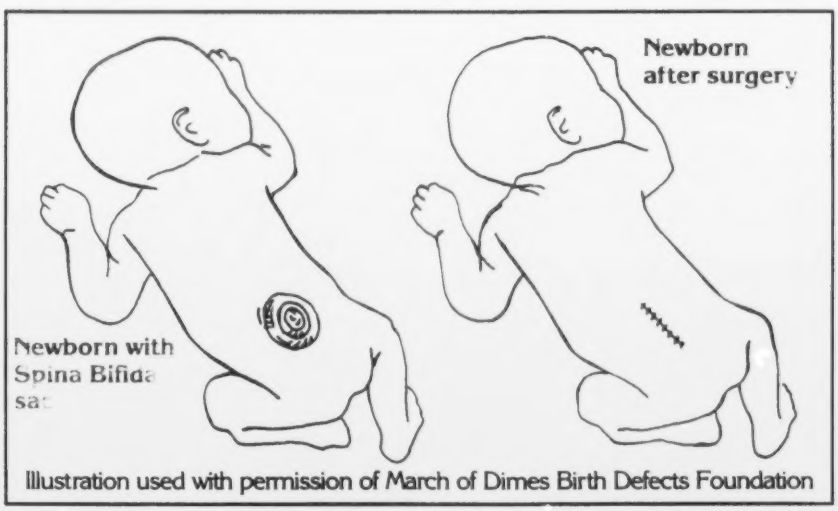
Before appointments, write down your questions and concerns for the doctor or other professional. During an appointment it is easy to forget to ask questions that have come up between visits. You may also find it useful to audiotape the doctor's instructions so that your spouse can hear the doctor's comments too. Your family can replay the tape later to review the instructions.

THE CHILD'S NEEDS

Infants and Toddlers with Spina Bifida — Ages 0 to 2

Health Care

- Continue regular health care as described in the Periodic Health Care section of this booklet. Remember that your child needs the same well-baby checkups and immunizations that all children need.
- Evaluation and treatment concerns for newborns include surgery to close the opening in the child's back. Surgery to insert a **shunt** will be necessary if **hydrocephalus** is present.



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- Infants and toddlers will need to receive a **neurological examination**, evaluation of their **head circumference**, intellectual and muscle development, hip stability, and nutrition. The health team will also watch the child's weight, height, and general development. The child usually needs to receive urine cultures and **bladder catheterization**, care of the skin of the legs, buttocks, and genital area. Dental care usually begins by age 2. Infants and toddlers also start physical therapy to promote muscle development and flexibility. Equipment can help the infant and toddler develop. They can be fitted with leg braces, **standing frames**, walkers, or wheelchairs.

- When children are hospitalized for surgery or other treatment, parents can help by providing comfort and support. Many children 6 months to 2 years old become anxious when separated from parents. However, children vary in their reaction to separation. Some children quickly become accustomed to new people and places, while others need more reassurance and comfort. Hospital staff know that families have other responsibilities. Understanding this, most hospitals have open visiting hours for family members.
- You may want to ask for assistance in planning home treatments and therapies.

Development

- Children develop faster as infants and toddlers than at any other time in life. Note the dates that your infant or toddler reaches developmental milestones. Some examples include cooing, babbling, saying the first word, reaching for a toy, and moving an object from one hand to the other. These may seem like small steps in development, but may be especially important because they help professionals understand your child better. Knowing how your child is developing also helps the health team make an appropriate treatment plan. Some parents monitor their child's progress in a baby book.
- Provide a safe environment and one in which your child can play with the least restriction. Keep in mind that your child lacks sensation in his or her legs and trunk. Provide toys and activities that are right for your child's stage of development.
- Adaptive equipment can help your child sit up and stand at the same ages other children do this. Using this equipment will help your child develop and expand his or her view of the environment. (See illustration: Aids for Progressive Development.)
- Expect the same standards of behavior for this child as any other child. Set appropriate limits on your toddler's behavior. All children need both love and discipline. Children who are not feeling well sometimes regress in their behavior. They may want parents to do things for them that they previously did themselves. This behavior is usually temporary and will end when the child feels well again.

Aids for Progressive Development

	3-5 months	6-9 months	7-12 months	10 months	12-14 months
Normal Development					
Stages of Development	looking around	using hands and arms	exploring the environment	standing	walking
Myelomeningocele					
	3-8 months	8-14 months		12-18 months	18 months-up

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School

- Public Law 99-457 mandates Early Intervention services for children from birth to 3 years who have special needs. In this program parents are partners in developing an **Individual Family Service Plan** (IFSP). The plan can include public health nursing services, occupational and physical therapy, educational services, respite care, and family education and support. Contact your local school district to find out how this program works in your area. Ask to speak to the Early Intervention Coordinator. Tell the coordinator about your child's condition and needs.

Child Care

- If you use day care, choose a provider who is willing to learn about caring for a child with spina bifida. Be sure you feel confident in the provider's ability to understand and carry out your instructions. Teach the provider about any treatments he or she may need to do.

- Develop an emergency plan with the day care provider. Write a list of reasons to contact you. Include phone numbers for you, your doctor, and several family members.
- A public health nurse in the local county health services or a social worker in county human services can help parents find **respite care** for families. The local Spina Bifida Association and Courage Center can help parents find babysitters who can care for children with spina bifida.

Preschool Children with Spina Bifida — Ages 3 to 5

Health Care

- Continue regular health care as described in the Periodic Health Care section of this booklet.
- Medical care may include a **CT Scan** (computed tomography) of head, a **renal ultrasound** (high frequency sound pictures of the kidneys), a neurological examination, measurement of head circumference, skinfold thickness, height, and weight. A urine culture is usually done every 3 months. A **voiding cysto-urethrogram** is often done to look for abnormalities in the urinary tract of children with bladder problems.
- Children this age will need a preschool evaluation, and will need to take part in activities that promote their ability to perform daily tasks independently. Continued physical and occupational therapy will promote development. Skin care is a concern for children of all ages with spina bifida.

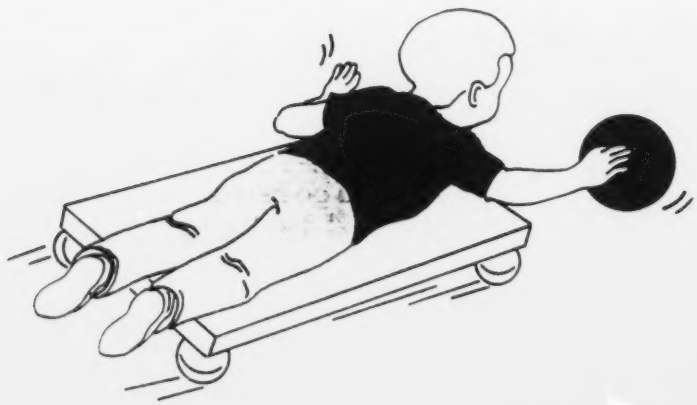
Development

- Provide your child with simple information about spina bifida. Teach them the names of equipment and how to use it.
- Expect the same standards of behavior for this child as any other child. Set appropriate limits on your child's behavior. All children need both love and discipline. Children who are not feeling well sometimes regress in their behavior. They may want parents to do things for them that they previously did themselves. This behavior is usually temporary and will end when the child feels well again.
- Bowel training and bladder emptying procedures are usually started during preschool years. Nurses and therapists can develop a plan for the child.

- A child's development can be stimulated if he or she has opportunities to
  - — Play with other children of the same age
  - — Learn to start and complete activities while playing
  - — Have a balance between structured activities and free time to play
  - — Succeed, to gain self-confidence

School

- Explore opportunities for preschool for your child. You may be able to send your child to a regular preschool as part of an Early Childhood Special Education program. In this program parents are partners in developing an **Individual Educational Plan** (IEP) for their child. Contact your local school district to find out how this program works in your area. Ask to speak to the Early Childhood Special Education Coordinator. Inform the coordinator of your child's needs and ask for an educational evaluation.
- At the beginning of each school year, meet your child's teachers and school nurse. Keep them informed of changes in your child's abilities, treatments, and medications. See the School section of this booklet for a list of specific topics to discuss with school staff.



School-Age Children with Spina Bifida — Ages 6 to 12

Health Care

- Continue regular health care as described in the Periodic Health Care section of this booklet.
- Medical care may include a CT Scan (computed tomography) of head, a renal ultrasound (high frequency sound pictures of the kidneys), a neurological examination, and measurement of head circumference. Procedures commonly performed for this age group include urological evaluation if your child has urinary problems and **orthotics** if needed. A urine culture is usually done every 3 months to watch for infection. Your child should also be evaluated for **scoliosis** or curvature of the spine each year.
- A nutrition evaluation (to prevent overweight) may be done yearly and includes a diet history, skinfold thickness, height, and weight.
- Continued physical and occupational therapy will promote your child's physical development and independence. Exercise helps keep muscles flexible in the child with spina bifida.
- Involve your child in planning daily treatment and therapy routines as much as possible.

Development

- School-age children understand factual information about spina bifida. Give them specific information about their condition. Provide them with opportunities to do their care and use equipment independently.
- Some children with spina bifida go into **puberty** early. Girls are more prone to early physical development than boys are.
- Allow your child increasing control over diet, medications, and therapy.
- Encourage your child to be responsible for remembering when to do treatments and take medications. Mastering self-care skills will give a child self-confidence and a feeling of accomplishment.

School

- Meet with your child's teachers and the school nurse at the beginning of each year. Keep them informed of changes in your child's abilities, condition, and treatment. See the information on schools in the Family Support and Services section of this booklet for a list of specific topics to discuss with school staff.
- **Adaptive physical education** classes can help the child with spina bifida get involved in exercise and sports with children their own age. Equipment such as racing chairs and hand propelled bikes help the child be active and independent. Courage Center offers information on equipment and transportation options. Contact your county human services office to locate local resources.
- If your child is absent from school, request that homework be sent home. If an absence lasts more than 15 days, request homebound services. A child is also eligible for homebound services if he or she is absent frequently or the doctor expects an absence to last more than 15 days.
- Encourage your child to get involved in group activities for children his or her age. Group activities promote social and physical development.

Adolescents with Spina Bifida -- Ages 13 to 17

Health Care

- Continue regular health care as described in the Periodic Health Care section of this booklet.
- Medical care may include a CT Scan (computed tomography) of the teenager's head, blood pressure check, a neurological examination, measurement of the teen's head circumference, skinfold thickness, and weight. These are usually done at least each year. Renal ultrasound (high frequency sound pictures of the kidneys) is usually done every 2 years. A urine culture is usually done every 3 months to check for infection. The doctor usually checks for scoliosis each year.
- A teenager with spina bifida may have a tendency to become overweight. If your teenager becomes overweight, meet with a registered dietitian to develop a well-balanced diet plan.

- Meet with a physical therapist to plan or adjust the teenager's exercise program. Remind the teen about the benefits of exercise.
- Adapt therapy to fit the teen's changing needs. Encourage your teen to talk to the therapist about a schedule that will not interfere with other activities.

Development

- Some teenagers benefit from belonging to a support group. You could find or start a support group for teens with physical handicaps. These groups offer a teen recreation and a chance to make friends with other teens who have similar concerns.
- Teenagers need to understand how spina bifida will affect their sexual and reproductive life. They may need encouragement to ask questions. Sexually-active teens need to protect themselves from sexually transmitted diseases and pregnancy. Discuss any specific concerns with the teen and your doctor.
- Some teens who are able to walk choose to use a wheelchair during adolescence. These teens feel they are more independent using a wheelchair. This may be a more difficult choice for the parents than for the teenager.
- Independence is necessary for teenagers to develop responsible behavior. They might need encouragement to become independent and to make the transition to adult life.
- Learning to drive is often very important to teenagers. In our society, it is a real step toward independence. Teenagers with spina bifida need special equipment on the car to learn to drive. **Adaptive driver education** is available at Courage Center.
- **Peers** become of increasing importance to teenagers. Young people with high self-esteem can resist negative **peer pressure.** They will also be less concerned about being different from their friends.

School

- When the teen is absent from school, arrange for him or her to receive homework from each class. If he or she is absent for more than 15 days in a row, request homebound services. Students are also eligible for homebound services if they are absent frequently or the doctor expects an absence to last more than 15 days.

- Encourage the youth to be an advocate for him- or herself in school. Teens can keep school staff informed of their needs and changes in their condition. At certain times during adolescence, teens may not be willing to do this. Parents need to be aware of how much information their teen has shared with school staff.
- Vocational counseling for teenagers with disabilities is provided through the school, beginning at age 14. Counselors can assist young people to look realistically at their strengths and abilities when choosing a career. Remember that all teenagers need encouragement to plan ahead.
- **Transitional programs** for independent living are an option for teens starting at about age 16. Ask your school or the Spina Bifida Association for information about these programs.

Young Adults with Spina Bifida — Ages 18 to 21

Health Care

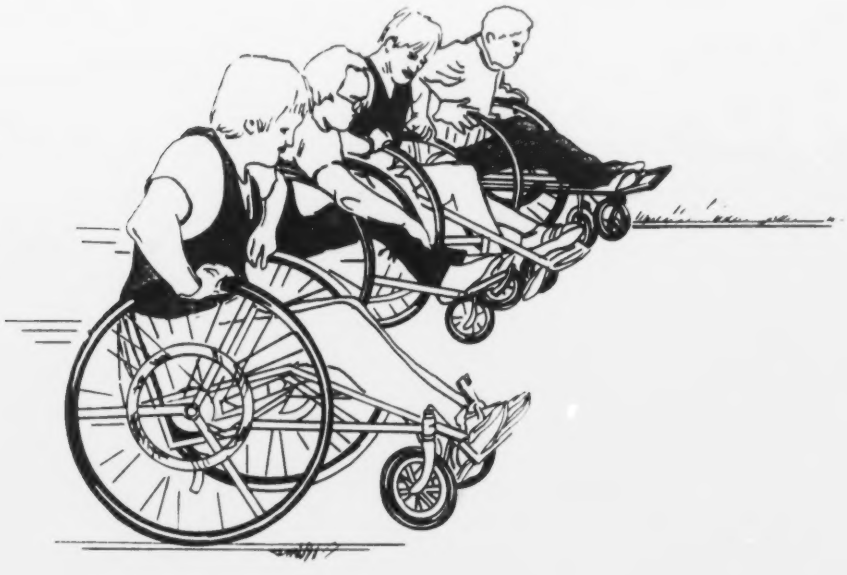
- Continue regular health care as described in the Periodic Health Care section of this booklet.
- Medical care may include a CT Scan (computed tomography) of the young adult's head, a neurological examination, measurement of head circumference, blood pressure check, a nutrition evaluation including measurement of skinfold thickness, height, and weight. A renal ultrasound (high frequency sound pictures of the kidneys) should be done about every 2 years. A urine culture is usually done every 3 months to check for infection.
- Young people who are planning to move away from home may need to find new health care providers. Also, young adults who have been seeing a pediatrician usually change doctors around age 18. You can ask your doctor to refer you to another specialist or primary doctor.
- Young people often need to plan to meet treatment needs within new schedules and activities.

Development

- Young adults focus on life goals and careers. If you are unsure of your career goals, you can get assistance in career planning from your school, Courage Center, or the Spina Bifida Association of Minnesota. Their addresses and phone numbers are listed in the Resources section of this booklet. Books about career planning for people with disabilities are available through the public libraries.
- Sexually-active young people need information to protect themselves against pregnancy and sexually transmitted diseases. Meet with a physician or nurse practitioner about family planning.

School

- Some colleges and schools are set up for wheelchair access. Check about ways the school will aid a person using a wheelchair before enrolling. Ask about handicapped accessibility, special help, transportation, driving, and health services.
- Some young adults plan for regular health care visits while they are home on vacation. It is a good idea to locate a physician near your school for illnesses and emergencies before one is needed.



FAMILY SUPPORT AND SERVICES

Advocacy

Parents of children with chronic conditions are advocates for their child. A lot of advocacy is just teaching people about your child's condition and needs. Parents understand their child's needs better than anyone else. Parents also have a lifelong relationship with their child. In contrast, health professionals come and go over time. Encourage your child to be an advocate for him- or herself too.

Another part of advocacy is being persistent in seeking a service or treatment that your child needs. If one person says you do not qualify for the service or that the child does not need a treatment, ask another person. Continue to tell health providers about your concerns until you are satisfied with their answers.

Finally, you may need to remind people who are treating your child to treat the whole child. Some health care providers will focus on one goal for the child's treatment, but may forget how that goal affects other areas of the child's life. An example of this is trying to fit treatments into a school schedule. You may need to discuss your child's treatment plan with school staff to best meet both treatment and school needs. If the treatment plan is not working well, ask health care providers if there are alternatives that would work better.

Human Services

When a family member has a chronic condition, the family may feel financially strained. Several medical financial resources exist for such families. Your local county human services office may help you find out if you are eligible for any of these. You may also call the agencies directly and ask them to send you eligibility information. See the health care financing information in the General Resources section of this booklet for organizations that offer medical financial assistance.

Schools

Each year when your child starts school, meet with teachers and the school nurse to discuss the following:

- Your child's written Individual Health Plan (IHP)
- Your child's experience with spina bifida
- Your child's abilities and strengths
- Your child's diet and fluid needs
- Equipment needs at school and how to use equipment
- Positioning and mobility needs
- Treatments and therapy at school: who is responsible, what can your child do (such as **catheterization**), where will it be done (need for privacy), when does it need to be done and best fit into the school schedule
- A plan for extended absences including receiving homework at home and homebound services
- A plan for notifying the school about changes in your child's condition or treatment
- When the school nurse or teachers should notify parents of illness or problems at school
- Your child's **Individual Education Plan** (IEP) for special education services

Family Support Groups and Networks

Sometimes it is helpful for parents to talk to other parents of children with spina bifida. Parents who have a child with the same condition can give encouragement and support with an understanding that comes from experience. You can find informal networks of parents through your doctor, pediatric nurse specialist, or social worker. The Association for the Care of Children's Health publishes a *Parent Resource Directory* that contains the names and addresses of families of children with chronic conditions across the United States. See the information on organizations in the General Resources section of this booklet for information on obtaining this directory.

Finding or starting a support group for teenagers with spina bifida may be helpful. It gives a teen the chance to talk to other teens with similar concerns. Support groups may also be available for families and siblings of teens with spina bifida. Family-to-family support can often give families insight into

options in managing spina bifida. Discussions may also help resolve the stress and emotional concerns that many families have. Check with your health care provider or local hospital to find out if there is a group in your area. If not, you may be able to start one with the help of a social worker or nurse.

Respite Care

Just as all parents of young children need a break now and then, so do parents of a child with spina bifida. **Respite care** may be an important part of your family's support plan. Having respite care available can give you a much needed night out or even a vacation. You may be able to teach a relative or friend how to do treatments. There are also home health services that provide this type of care. Some counties have respite programs. Inquire at your county human services office, public health nursing service, or doctor's office for a list of quality respite care services.

Transportation

Rehabilitation centers can help families plan to meet transportation needs as those needs change during the child's development. Some also offer adaptive driver education for teenagers and adults.

Recreation

Most activities can be adapted so children with **impaired mobility** can participate. Some schools and communities may have special recreational activities for children and teens with limited mobility. You can locate these by contacting the special education office in your school district and local parks. Inform group leaders or coaches of your child's abilities and special needs.

Exercise is an extremely important part of spina bifida treatment. It improves stamina and keeps muscles flexible. Exercise may decrease the need for physical therapy treatments.

Travel

Traveling with a child who has spina bifida may require extra planning, but can be enriching for the whole family. Make a list of equipment and belongings that you need a few weeks before your trip. If **adaptive travel and lodging** are needed, families need to prepare well in advance for the trip. Contact airlines, lodging facilities, and recreation areas before leaving home to make sure they can meet your family's needs. This may make the trip go smoother. Ask your doctor, nurse, and therapist for helpful hints on planning for your child's health needs when traveling. Be sure to bring your health insurance card along. The International Association for Medical Assistance to Travellers (IAMAT) will help members locate an English-speaking doctor in foreign countries. See the information on organizations in the General Resources section of this booklet for more information.

Siblings

The brothers and sisters of a child with special health care needs have concerns other children don't have. They have many adjustments to make. They may have mixed feelings about their responsibility to the child with special health care needs. They may feel guilty about being normal. They may also be angry that they do not receive as much "attention" as the child with special needs does.

Parents can help siblings adjust in several ways. Parents can give each of their children individual time without interruption. They can assure their children who don't have spina bifida that their feelings are okay. Relationships between siblings should stress friendship rather than caregiving. The siblings of a child with special needs may benefit from the support of a person outside the immediate family. This may be a relative or a trusted friend. Other resource people may include school teachers, coaches, counselors, and spiritual leaders. With support, children can grow through the experience of having a sibling with special health care needs!

GLOSSARY

Adaptive physical education - Physical education classes that are changed to make it possible for students with disabilities to participate.

Adaptive travel and lodging - Transportation and lodging that is made to accommodate people using wheelchairs.

Alpha fetoprotein - A blood test to determine if certain severe genetic conditions are present in a fetus (unborn child).

Arnold-Chiari Malformation - A deformity of the back part of the brain, in which the cerebellum and brain stem are displaced into the spinal canal. It does not often cause problems, but in some children under 5 years it can cause feeding problems and breathing problems.

Bladder catheterization - Draining urine from the bladder with a tube through the urethra.

Blood levels - A blood test to check the amount of a medication, such as an antiseizure medication, in the blood.

Chronic condition - A disease or disability that affects a person for a long time; often for their whole life.

Clubfoot - A deformity of the feet that causes them to turn too far inward.

Community-based care - Services available as close to home as possible; within the community as defined by the family; includes the local doctor, clinic, outreach specialty clinics, the public health nurse, the school, public and private agencies.

CT Scan - Computed tomography. A detailed x-ray of the body or brain; a sectional x-ray.

Culturally sensitive - Care that is responsive to the values, beliefs, social norms, and behaviors of the individuals or populations being served; recognition of the values of different population groups. (Definition from New England SERVE)

Culture - A laboratory test for growing bacteria (or sometimes viruses or fungi) to identify the type of microbe causing an infection.

Developmental delay - This occurs when children have not begun certain activities by the age that most children do. Developmentally delayed children may be slow to learn to talk, walk, feed and dress themselves, read, write, or perform other activities.

Developmental milestones - When children begin an activity that is a big step in their development, such as crawling, walking, saying words, or other activities.

Environment - In this context, the area that surrounds the child; where the child lives, plays, goes to school, and visits.

Environmental factors - Things in the environment that can cause a health problem.

Epilepsy - A brain disorder that causes seizures.

Family-centered care - Health care that recognizes the family as the constant feature in the child's life, that is flexible, accessible, and responsive to family needs.

Family-centered health care team - A group of health professionals who work together with the family to provide the best care for each child with special needs.

Generic name - A drug name not protected by trademark; usually descriptive of the drug's chemical structure. Aspirin is a generic name.

Genetic counseling - A service to help families find out the risk of having a child with a birth defect, an inherited or genetic condition. Genetic counselors may be physicians or other health professionals who specialize in genetics; services are often provided at a genetic counseling clinic where special tests can be done.

Genetic factors - Defects in the genes that can cause inherited conditions.

Habilitation - Activities and therapies that help a child with a chronic condition develop independence and self-sufficiency; sometimes called rehabilitation.

Head circumference - Measurement around the largest part of the head; done frequently with infants and young children to check for hydrocephalus.

Hydrocephalus - A condition in which pathways for spinal fluid are blocked, causing an enlarged head because of accumulation of fluid around the brain; a shunt is put in to correct this condition by draining the extra fluid.

Impaired mobility - A person who has difficulty moving around without support or special equipment.

Individual Education Plan (IEP) - A plan for children receiving special education services; to meet a child's unique learning needs with a detailed plan. Parents are members of the team that develops the plan.

Individual Family Service Plan (IFSP) - A plan to meet the unique needs of children with special needs from birth to 3 years and their families; developed by a multidisciplinary team including the parents.

Learning disability - Any of a number of problems with learning in people of normal intelligence; dyslexia is one type of learning disability.

Meningocele - A birth defect in which the covering of the spinal cord and nerves protrude spinal cord in the sac.

Multidisciplinary team - A group of professionals from different fields who work together to give specialized services to the family.

Myelodysplasia - A large group of malformations of the spinal cord, of which spina bifida is most common.

Myelomeningocele - A birth defect in which the spinal cord and nerves protrude through a defect in the spinal column; same as spina bifida cystica or spina bifida aperta.

Neurological examination - A detailed physical examination that focuses on the function of the brain and nervous system.

Nutritional status - How well a person's diet is meeting their nutritional needs.

Oral medication - A drug taken by mouth or swallowed.

Orthotics - Adaptive equipment such as braces, splints, standing frames, and chairs.

Peer pressure - Demand or influence of peers on the person's choices; it can be positive or negative peer pressure.

Peers - In this context, children of the same age who know each other.

Puberty - The period of time when sexual maturation occurs, often between 12 and 17 years.

Renal ultrasound - A picture of the inside of the kidneys made using high frequency sound waves.

Respite care - Care given by people outside the immediate family to give family members a rest from caregiving responsibilities.

Scoliosis - An abnormal side to side curve of the spine.

Seizure - A sudden attack; often a short, sudden loss of function because of interrupted electrical activity in the brain.

Shunt - A tube that goes from the brain to the abdomen to drain extra fluid in patients with hydrocephalus.

Spina bifida - A defect in the formation of the spinal column.

Spina bifida occulta - A mild form of spina bifida with a small defect in the spine, with no paralysis or sac.

Standing frame - A device that supports the child in a standing position.

Therapeutic range - The blood level of a medication that produces the desired effect without severe side effects.

Trade name - The brand name of a medication, such as Tylenol; protected by trademark.

Transitional programs for independent living - Programs that help teenagers or young adults and their families prepare for moving away from home and being responsible for themselves.

Transitional residence program - A place for young adults to live and learn the skills needed to live independently.

Urethra - The tube goes from the bladder to the outside, to drain urine from the bladder.

Vertebrae - The bones of the spine.

Voiding cysto-urethrogram - An x-ray of the bladder to check for structural problems.

RESOURCES
for Children with Spina Bifida

Organizations

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55411
(612) 588-0811

Courage Center offers home based services for physical therapy and occupational therapy. Other services include camping career counseling and vocational services, home modifications, a **transitional residence program**, support groups, adaptive driver's education, and recreational and athletic activities.

March of Dimes Birth Defects Foundation
1275 Mamoroneck Avenue
White Plains, NY 10605
(914) 428-7100

March of Dimes offers publications about birth defects to families and professionals. Information about genetics and heredity of some conditions is also available.

National Hydrocephalus Foundation (NHF)
22427 South River Road
Joliet, IL 60436
(815) 467-6548

This organization offers a quarterly newsletter to parents, arrticles and videotapes about hydrocephalus to families. Call or write for information.

Spina Bifida Association of America (SBAA)
1700 Rockville Pike, Suite 250
Rockville, MD 20852
(800) 621-3141
(301) 770-7222

This organization offers information to families and health professionals about spina bifida. It also publishes a newsletter called *Spina Bifida Insights*, which is free to members of SBAA.

Spina Bifida Association of Minnesota
Box 29323
St. Paul, MN 55429-0323
(612) 222-6395

This organization offers support and information to families with a member who has spina bifida. It also provides monthly chapter meetings, a monthly newsletter, a parent outreach program for new parents, a lending library, and an equipment loan program.

TASH — Association for Persons with Severe Handicaps
7010 Roosevelt Way N.E.
Seattle, WA 98115
(206) 523-8446

This is an organization of parents and professionals. It works to improve programs for people with severe handicaps. Call or write to the national organization for current information about the Minnesota chapter.

Books and Pamphlets
for Children and Families

Many of the books listed here are available through the Minnesota public library system. Books that are not available at the local library can be borrowed from any public library in Minnesota.

Barish, F. 1984. *Frommer's A Guide for the Disabled Traveler.* Simon and Schuster, New York, NY.

Bennett, C. 1980. *Giant Steps for Steven.* Spina Bifida Association of America, Rockville, MD. This book is for preschool and school-age children. It is written by Steven's mother. It contains photographs and a story about Steven's daily life. Steven is a 4 year old with spina bifida.

Bloom, B., and Seljeskog, E. 1988. *A Parent's Guide to Spina Bifida.* University of Minnesota Press, Minneapolis. 86 pages. This is a guide to state-of-the-art health care and comprehensive treatment for children with spina bifida. It is written especially for the parents of these children.

Rabe, B. 1981. *Margaret Moves.* Dutton, New York, NY. This book written for school-age children and adolescents. It is a novel about 10 year old Margaret, who has spina bifida. The story is about her determination to keep up with other children and get some things she wants.

Roy, R. 1985. *Move Over, Wheelchairs Coming Through!.* Clarion Books, New York, NY. 83 pages. This book is written for school-age children and teenagers. Text and photographs tell the stories of seven disabled youth between the ages of 9 and 19 who use wheelchairs in their active lives.

St. Germaine, A. 1986. *Resource Manual for Physically Disabled Adolescent.* Gillette Hospital Interdependent Living Clinic, University of Minnesota Myelomeningocele Clinic. This manual contains Minnesota and national resources for youth. Topics include newsletters, funding sources, camps and special programs, social and recreational programs, counseling, transportation, residences, and transitional programs.

TeGrootenhuis, G. 1982. *Street Wheeling Manual.* Metropolitan Center for Independent Living, St. Paul, MN. This booklet is about wheelchairs and mobility.

White, P. 1978. *Janet at School.* Crowell, New York, NY. This book is written for preschool and school-age children. In it, 5 year old Janet describes her daily life and abilities as a child with spina bifida. It contains many color photographs of Janet.

Wolraich, M. 1983. *The Needs of Children with Spina Bifida: A Comprehensive View.* University of Iowa, Iowa City, IA. This 34-page booklet includes an overview of spina bifida, describes the service needs of children with the condition and outlines coordination of services.

Articles
for Health Professionals

Brizee, L. 1988. Nutritional concerns associated with spina bifida. *Nutrition News, Improvement of Nutrition Services for Children with Handicaps or Chronic Illnesses. 3(4).*

Kazak, A. 1986. Stress in families of children with myelomeningocele. *Developmental Medicine and Child Neurology.* 28(2):220-228.

Liptak, G., et al. 1988. The management of children with spinal dysraphism. *Journal of Child Neurology.* 3(1): 3-20.

Mississippi Medical Association. 1987, 1988. Orthopaedic management of myelomeningocele. *Journal of the Mississippi State Medical Association.* Series of articles include:

- Neurologic complications, June 1987: 145-150.
- Neurosurgical treatment, July 1987: 173-176.
- Urologic management, Aug. 1987: 209-212.
- General orthopaedic management, Sept. 1987: 235-240.
- Specific orthopaedic procedures, Nov. 1987: 299-302.
- Myelomeningocele: adolescence/sexuality/vocational skills, Feb. 1988: 45-46.
- The primary care physician's role in management of the patient with myelomeningocele, March 1988: 75-77.

Ohio Department of Health. 1987. *Standards of Care for Children with Myelomeningocele.* 2 pages. These standards were prepared to assure that children with myelomeningocele receive treatment to achieve maximum habilitation.

Smith, K. 1990. Bowel and blader management of the child with myelomeningocele in the school setting. *Journal of Pediatric Health Care.* 4:175-180.

Wolraich, M. 1983. *The needs of children with spina bifida: A comprehensive view.* University of Iowa, Iowa City, IA. 34 pages.

Specialty Medical Care for Children with Spina Bifida

Specialty medical care for the child with spina bifida usually includes a pediatric neurologist, an orthopedist, a physiatrist, and other specialists. Individual children's needs for these services will vary. The organizations listed here offer health care services to children with spina bifida.

Children's Hospital of St. Paul
345 North Smith
St. Paul, MN 55102
(612) 220-6000 or 220-6700

Gillette Children's Hospital
200 East University Avenue
St. Paul, MN 55101
(612) 291-2848

Park Nicollet Medical Center
Pediatric Subspecialty Clinic
910 East 26th Street
Minneapolis, MN 55404
(612) 871-1024

University of Minnesota
Pediatric Neurology Clinic
Phillips-Wangensteen Building, 4th Floor, Box 88
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-6777

Please note:

This is a partial list of resources available in Minnesota. We do not endorse any specific organizations or publications. You will need to evaluate the quality of the services and determine if they fit your individual situation.

GENERAL RESOURCES

for Children with Special Health Care Needs

Organizations

Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

ACCH publishes a variety of materials for families and professionals. It offers a newsletter, brochures and booklets, and videos to help families get the most out of the health care system. It also publishes the *Parent Resource Directory,* which contains the names and addresses of parents whose children have special health needs. Parents are listed by area and by their child's condition. The Minnesota chapter is coordinated by a parent. Call or write the national organization to for the current chapter address. Send for the ACCH publications catalog.

County Public Health Nursing Agencies
Minnesota Department of Health
Section of Public Health Nursing
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5468

Each county in Minnesota offers public health nursing services to residents of the county. Some counties offer respite care services or can help families locate respite care. The local agency may also help teach family members and babysitters about the care of the child with special health care needs. Contact your local county, or call the Minnesota Department of Health to locate your local office.

County Social Services
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-6117

County social services offer support and assistance in finding local resources for families such as equipment, respite care, financial aid and intervention services. It also offers care coordination to families. Call your local county for information.

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
(612) 588-0811

Courage Center offers services to children and adults with physical disabilities and speech, hearing and vision impairments and services are also available to family members. It offers adaptive driver education, a Communication Resource Center, camping experiences, a transitional residence program, support programs, physical and occupational therapy, and recreational and athletic activities. *Meeting Ground* is a free bimonthly newsletter written by and for families and health professionals. Call or write for a subscription.

The Early Intervention Project
Minnesota Departments of Health, Education and Human Services
Call your local school district for information.

The Early Intervention Project is a federally mandated program that operates through local interagency committees. Its purpose is to provide services for children from birth to three years of age who have special health care needs or developmental delays. Services may include respite care, public health nursing services, physical therapy, occupational therapy, speech and language therapy, early childhood special education, special equipment, family support activities, and training for parents.

Federation for Children with Special Needs
95 Berkeley Street
Boston, MA 02116
(617) 482-2915

The Federation for Children with Special Needs provides information and resources that focus on improving communication between families and health professionals. It also offers support for parents of children with special needs.

International Association for Medical Assistance to Travellers
IAMAT - USA Membership Office
417 Center Street
Lewiston, NY 14092
(716) 754-4883

IAMAT is an organization that publishes a directory of English-speaking physicians around the world. Fees for visits are set at

low rates. It also offers health information for travelers. The membership and directory are free. Voluntary contributions are encouraged.

MedicAlert Foundation International
Turlock, CA 95381-1009
(800) ID-ALERT

MedicAlert makes identification necklaces and bracelets. The tags list medical information such as diagnosis, medications, and allergies. When someone purchases an ID, MedicAlert keeps a brief medical record on computer, which is updated yearly. Emergency medical personnel can call for more specific information than can be listed on the ID.

Metro Center for Independent Living (MCIL)
1619 Dayton Avenue, Suite 303
St. Paul, MN 55104
(612) 646-8342 (voice or TDD)
(612) 642-2507 (FAX)

MCIL offers transitional programs to promote independent living. Its Used Equipment Referral Service is a network between sellers, buyers, and donators of used equipment. It matches people who need equipment with those who have equipment available. Equipment includes wheelchairs, bathroom equipment, ramps, lifts, vehicles, hospital beds, walkers, prone standers, and more.

Minnesota Department of Health
Genetics Unit
717 SE Delaware Street
Box 9441
Minneapolis, MN 55440
(612) 623-5269

Families can call the Genetics Unit to locate resources for genetic counseling for conditions that have a possible hereditary component.

Minnesota Department of Health
Services for Children with Handicaps (SCH)
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free voice or TDD)

SCH offers community-based clinics and services, health education and support programs, and health care financing to families of children with special health care needs. It also offers technical consultation to health professionals. SCH has district offices in Bemidji, Duluth, Fergus Falls, Mankato, Marshall, Minneapolis, Rochester, St. Cloud, and Virginia. Call for more information.

Minnesota State Council on Disability
145 Metro Square Building
7th Place and Jackson Street
St. Paul, MN 55101
(612) 296-6785 (voice or TTY)
(800) 652-9747 (Ask for Minnesota State Council on Disability)
This is an information and referral resource for people with disabilities who live in Minnesota.

National Center for Youth with Disabilities
Adolescent Health Program
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(800) 333-6293
The center offers services to families, youth, and professionals to assist them in developing alternative service systems, which will allow adolescents and young adults to develop to their fullest capacity. It offers a National Resource Library and technical assistance by a network of professionals from many disciplines. The center also fosters the development of community-based services through a national network of federal and state information.

National Information Center for Handicapped Children and Youth (NICHCY)
P.O. Box 1492
Washington, D.C. 20013
(703) 893-6061
NICHCY is a national clearinghouse that provides information about many handicapping conditions. It also offers a list of parent groups throughout the United States and information regarding available services to disabled people.

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
(800) 346-2742

This organization offers a computer information service called ABLE DATA. Call for information.

PACER Center (Parent Advocacy Coalition for Educational Rights)
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966 (voice & TDD)
(800) 53-PACER (toll-free)

PACER Center offers statewide workshops for families of handicapped children. The workshops inform parents of schools' rights and responsibilities to provide free appropriate education programs for children. Specific information is provided about Public Laws 94-142 and 99-457. Written materials are available in English, Spanish, and Hmong languages.

Pathfinder Resources
2324 University Avenue West, Suite 105
St. Paul, MN 55114
(612) 647-6905

Pathfinder works to improve the health and well-being of children with chronic conditions. It offers consultation and technical assistance in networking, education, public policy and financing, and publications.

Pilot Parents of Minnesota
201 Ordean Building
Duluth, MN 55802
(218) 726-4745

Pilot Parents is a parent network that matches families who have children with similar health or developmental conditions. Parents are trained to give information about services and educational programs, and can offer emotional support. Parents are available in most areas of Minnesota including northeastern, northwestern, central, and southeastern Minnesota. Pilot parents hope to have families available in southwestern Minnesota in 1991.

Siblings for Significant Change
105 East 22nd Street
Room 710
New York, NY 10010
(212) 420-0776

This Organization for siblings of disabled people. It offers information and referral services, counseling programs, and community education.

Sibling Information Network
Connecticut's University Affiliated Program
991 Main Street
New Hartford, Connecticut 06108
(203) 282-7050

This is a clearinghouse of information for the siblings and families of disabled people. It offers quarterly newsletters with reviews, resource information, and discussions of family issues.

Wilderness Inquiry
1313 Fifth Street SE
Suite 327A
Minneapolis, MN 55414
(612) 379-3858

Wilderness Inquiry provides challenging wilderness experiences for physically disabled and nondisabled people. The camping trips require interdependence and cooperation. Experiences are available for families with children. Young adults over 18 years old may attend without family members. Some trips are available to teens 13 to 18 years old.

Books, Pamphlets, Videos, and Catalogs of Information

Adams, B. 1979. *Like It Is: Facts and Feelings about Handicaps from Kids Who Know.* Walker & Co., New York, NY. 96 pages. This book is written for school-age children and adolescents.

Aspen Publications. *Infants and Young Children.* 1600 Research Boulevard, Rockville, MD 20850. This journal is for parents and professionals who work with children. For more information phone (800) 638-8437.

Association for the Care of Children's Health, 1987. *Family-Centered Care for Children with Special Health Care Needs.* ACCH, Bethesda, M.D. 74 pages. This book describes family-centered health care. Each chapter has a section that contains specific ideas to "make it happen." The final chapter includes checklists to help evaluate how well health providers are collaborating with families.

Association for the Care of Children's Health, 1988. *Seasons of Caring.* ACCH, Bethesda, M.D. 40-minute videotape. Reveals the strengths and needs of families caring for children with special health care needs. Addresses many issues encountered by parents, teachers, social workers, school administrators, nurses, physicians, and others who care for children with special needs and their families. Another 38-minute video, *Family-Centered Care,* shows the experiences of several families around the country.

Beckett, J. 1990. *Health Care Financing: A Guide for Families of Children with Special Health Care Needs.* National Maternal and Child Health Resource Center, University of Iowa, Iowa City, IA, 52242. 77 pages. This publication is an introduction to private and public funding. It also includes a private insurance checklist and a resource list.

The Exceptional Parent. 605 Commonwealth Ave., Boston, MA 02215. This is a consumer magazine for parents of children with chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Exley, H. (editor). 1984. *What It's Like to be Me.* Friendship Press, New York, NY. 127 pages. This book is written and illustrated entirely by disabled children. It's intended for school-age children and those in early adolescence.

Haig, B. and Moynihan, P. 1988. *Whole Parent/Whole Child: A Parent's Guide to Raising the Child with a Chronic Health Condition.* Diabetes Center, Minneapolis. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Harnish, Y. and Leeser, I. 1984. *Patient Care Guides: Practical Information for Public Health Nurses.* National League of Nursing, New York, NY. 211 pages. This book has a section that contains patient care guides for children with chronic conditions. Some of the conditions included are mental retardation, myelodysplasia, neurological handicaps, muscular dystrophy, and cleft lip and palate.

Healy, A. and Lewis-Beck, J. 1987. *Guidelines for Families, Guidelines for Nurses, Guidelines for Physicians, Guidelines for Social Workers, Guidelines for Therapists.* University of Iowa Bookstore, Iowa City, IA 52242. Each of these booklets describes specific actions that can improve health care of children with chronic conditions.

Imagine Me. 1987. Innercare, 322 First Avenue North, Suite 320, Minneapolis, MN 55401. (800) 727-7794. *Imagine Me* is a learning kit to help children with chronic disorders that cause discomfort learn to control their distress. It includes audiotapes for the child and parents, a practice book, a progress chart, tools, and a "Body Boss" Bear.

Larson, G. (Editor), 1986. *Managing the School Age Child with a Chronic Health Condition.* Pathfinder and the School Nurse Organization of Minnesota, DCI Publishing. 335 pages. This book is a practical guide for schools, families, and organizations. A family may find it useful to review and discuss chapters about its child's condition with school personnel.

Mitchell, J. 1980. *See Me More Clearly: Career & Life Planning for Teens with Physical Disabilities.* Harcourt Brace Jovanovich, New York, NY. 284 pages. A comprehensive guide for youth with disabilities. Includes a section titled "Charting Your Course: Life Career Skills."

National Center for Education in Maternal and Child Health (NCEMCH). 1989. *Reaching Out: A Directory of National Organizations Related to Maternal and Child Health.* 38th & R Streets, NW, Washington, DC. This resource guide lists organizations by specific disease or disability.

National Maternal and Child Health Clearinghouse (NMCHC) 1988. *Publications Catalog.* 38th & R Streets NW, Washington, DC 20057. 22 pages. Catalog of publications available through NMCHC. Most of these publications are free. One section lists publications about children with special health care needs.

Neibuhr, S., and Royse, J. 1989. *Take Care.* Wilder Foundation, 919 LaFond Avenue, St. Paul, MN 55104. (612) 642-4060. 31 pages. A guide for caregivers on how to improve their self-care.

Pediatrics for Parents. This newsletter is written to help parents understand pediatrics and health care issues so they can become informed, active participants in their child's health care. 10 issues per year. Write or phone for subscription information: Pediatrics for Parents, 348 Broadway, PO Box 1069, Bangor, MD 04401. Phone (207) 942-6212.

Randall-David, E. 1989. *Strategies for Working with Culturally Diverse Communities and Clients.* Association for the Care of Children's Health. Bethesda, M.D. 96 pages. This guide is written to help professionals learn to provide culturally appropriate care to families and communities. It includes sections on assessing your own cultural heritage, learning about the community, working with culturally diverse groups and using interpreters.

Routburg, M. 1986. *On Becoming a Special Parent: A Mini-Support Group in a Book.* Parent/Professional Publications, Box 59730, Chicago, IL 60645. Chapters on adjustment, equipment and toys, hospitals, respite, health care, medication, therapy, advocacy, individualized education program (IEP), and more.

Segal, M. 1988. *In Time and With Love: Caring for the Special Needs Baby.* Newmarket Press, New York, NY. 192 pages. For families and caregivers of preterm and handicapped children ages birth to 3 years. Information is included about coping; nursing, feeding, and dressing; social skills; games and activities; discipline; and decision making.

Health Care Financing

There are many types of health care financing available to families with children with special health care needs. Each plan covers different services. Eligibility requirements also differ. Listed are some of the most common payment systems. Contact your local county human services office or the providing agency to find out if you are eligible for any of these.

Children's Health Plan (CHP)

444 Lafayette Road
St. Paul, MN 55155-3829
(612) 297-3862
(800) 652-9747 (Ask for Children's Health Plan)

The Children's Health Plan offers health care insurance for under insured or uninsured children 1 through 17 years old. Coverage costs $25 per year, per child. Eligibility is based on income and family size.

Medical Assistance Program (MA)

Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-3386
(800) 652-9747 (Ask for Medical Assistance)

Medical Assistance offers health care financing for families. Eligibility is based on income and family size. Children with chronic health conditions may qualify for full Medical Assistance benefits based on their income and assets alone under a waiver. For information, call your county human services office or the state office listed here. Local county human service agencies may also have funds under Title XX Social Service Programming, Family Subsidy, or Permanency Planning Grant.

Waivers

Waivers provide medical assistance benefits to children counting only the child's income and assets to determine eligibility. Expenses covered vary with each type of waiver.

Children's Home Care Option (TEFRA 134)

Medical Assistance is offered under the Children's Home Care Option or TEFRA. Children must be certified as disabled by the Social Security Administration or the State Medical Review

Team. Children are cared for at home. Eligible children have all regular medical assistance expenses covered.

Community Alternative Care (CAC)
The program offers home and community care services for chronically-ill children. Children must be residents of a hospital or be likely to need inpatient hospital care. The program covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Community Alternatives for Disabled Individuals (CADI)
This program covers applicants to or residents of nursing care facilities. The person must be certified as disabled. Children are cared for at home. The program offers home and community care services for disabled individuals under age 65. It covers expenses for care that cost less than they would at an institution covered by Medical Assistance.

Home and Community Based Waiver for Persons with Mental Retardation or Related Conditions (MR/RC)
Individuals diagnosed with mental retardation or a related condition of any age are eligible. The person is cared for at home. This waiver covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Services for Children with Handicaps (SCH)

Minnesota Department of Health
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free, voice or TDD)

Services for Children with Handicaps offers financial help for health care to children with special health care needs. Eligibility is based on diagnosis, income and number of family members. SCH serves children from birth to age 21 years. Services for Children with Handicaps has district offices in Bemidji, Fergus Falls, Virginia, Duluth, Marshall, St. Cloud, Minneapolis, Mankato, and Rochester.

Minnesota Department of Health
717 Delaware St. S.E.
P.O. Box 9441
Minneapolis, MN 55440